

## ARTICLE

# Listening Beyond Words: Swinging Together

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This paper draws on the making of a short video, called *Swinging Together*, produced in the context of an artistic participatory research project with people communicating beyond words. Our aim is to investigate how new materialist theories disrupt the production of ‘voice’ while working with a person labeled as ‘non-verbal’. We critique dominant functionalist and medical perspectives which reify ‘non-verbal’ only as a lack. In disrupting ‘voice’, we learn how important it is not to search for a magical closure, a final singular form, or (special) method with instructions to follow, but to focus on the relational and procedural. Concepts as ‘leading-following’ (Manning 2009) ‘voice without subject’ (Mazzei 2016) and ‘bodying’ (Manning 2016) shape our encounter with Heleen, an 18-year-old young woman commonly considered as autistic, non-verbal, strange, and out of place. In scrutinizing concrete practices which she desires we are searching to make sense of how Heleen experiences the world.

**Keywords:** non-verbal; autism; swinging; voice without subject; leading-following; bodying

I want to begin here, in the midst of a paradoxical experience where on the one hand there is difficulty as regards initiation and follow-through, where there are real challenges with communication and body-movement alignment, and on the other hand there is an acute richness of relational intensity that facilitates a perhaps more complex encounter with the world in-forming. (Manning 2016: 115)

## 1. Introduction

The categories of the human and even of selfhood have been dominantly linked to voice and more specifically to words and speech. In general, voice has frequently been privileged on the assumption that, emanating from a subject who uses transparent and comprehensible language in order to create coherent and linear narratives, it represents the truth of consciousness and experience. This notion of voice, tied to a subject ‘who knows who she is, says what she means and means what she says’ (MacLure 2009: 104; Mazzei and Jackson 2009: 1) is a fundamental tenet of our neurotypical<sup>1</sup> world and imperative to be recognizable as human. This paper aims to expand this neurotypical understanding of the subject and voice because it positions those who struggle to use words or those who are labeled as non-verbal and minimal verbal too easily not only in the margins, but often outside the human category.

This negative view is corollary to the dominant functionalist and medical perspective that reifies non-verbal as lack, deficit, problem of disordered brains, silence to overcome. Furthermore, someone who needs facilitation to communicate is frequently understood as being dependent, as being incapable of directing their own experience and of having knowledge.<sup>2</sup> In order to deal with this ‘lack’, many person-centered interventions are developed in healthcare and (medical) rehabilitation. They are mainly focused on repairing or reviving the hitherto ‘broken’ or ‘lost’ voice as well as on making the non-verbal subject as independent as possible.<sup>3</sup> The existing small amount of literature on the

<sup>1</sup> Our definition of ‘neurotypicality’ is mainly based on Erin Manning’s work, who describes it as an often invisible and unspoken identity politics that predefines which lives, voices and experiences we value and what counts as knowledge. It takes for granted what the human should be and limits of what human subjectivity might look like. It also includes other forms of oppression, as racism, classism, and sexism (Manning 2016: 136).

<sup>2</sup> Childhood research has also struggled with and continue to struggle with the fact that children being labelled as dependent, incapable, and so forth. Methodologically, therefore, we find support in the work of, among others, Eldén (2013).

<sup>3</sup> Examples of such interventions are: Reminiscence Therapy (Woods et al. 2005), Validation Therapy (Bleathman et al. 1992), verbally based communication interventions, such as Focused Playtime Intervention (Siller et al. 2013), Prelinguistic Milieu Teaching (Yoder 2006), Discrete Trial Training (Lovaas 1987), alternative and augmentative communication (AAC) training such as Picture Exchange Communication System (for a review see Brignell et al. 2018).

minimal-verbal, non-verbal or other-verbal is imbued by the deficit model and mainly focuses on the methods and effects of therapeutic interventions. Experiences of non-, minimal- or other-verbal people are hardly addressed, and their voices are rarely included in what we understand as knowledge-formation (Biklen 2005; Manning 2016; Quinn 2017, 2019; Savarese 2010).

In this article we want to reconceptualize 'voice'. Drawing on the work of Mazzei and Jackson (2009, 2012, 2016, 2017) we investigate how posthuman and new materialist theories support us in disrupting the normative production of 'voice' when working with a person labeled as 'non-verbal'. In this disrupting, we are explicitly not aiming for an expansion of the privileged imaginary of voice. We rather engage with the urge present in crip theory and focus on creation and transformation; we re-imagine what voice could mean and how we can reconfigure our ways of relating and depending on what we came to understand as voice (Kafer 2013). Is voice limited to language and sound? Does voice need to be bound to one human mouth, throat, or vocal cord? Or can it be created in entanglement with the more-than-human and what does that entail in the lives of people carrying the label of non-verbal and their families? These questions are crafted and intuited in our relationship with Heleen, an 18-year-old young woman commonly considered as autistic, non-verbal, strange, and out of place. In what follows, we explicitly consider how our encounters with Heleen evolve and how they shape and influence the inquiry itself – this means we foreground process rather than product. Our encounters generate large amounts of what Ken Gale would call 'data events'. Conceptualizing data as event/ful serves to displace the discursively dominant idea that data somehow are fixed objects that can be captured and analyzed (Gale 2018: 94). Data as event/ful is about transmutations and flux, where multiple entanglements of materiality and discourse are the vibrant matter of agentic assemblages. These kinds of entanglements intra-act with the inquiry itself.

Not only are data not fixed objects, also the ethical procedure behind this research is not fixed and unambiguous. In the context of working with Heleen, we had first to settle for what our ethical research committee asked and work with notions as assent and consent. Here we already encounter a problematic paradox: the procedure of assent and consent presents a binary thinking of capable versus incapable, adult versus child, in which we also notice a strong hierarchical undertone. What if you cannot fit a person into these strict boxes? To let Heleen participate in this research we legally could ask for consent. The information form and letter for participation is a standard one without adaptations (for instance, without working with symbols or images). Heleen's parents read the form with her. In fact, the whole family was involved from the very beginning: we never do anything without notification of Heleen, her parents, and her sister. This means that we could legally work with Heleen's consent, but that it is at the same time more like working with assent (and consent for the parents and sister). However, our ethical work does not stop with these forms or concepts of assent and consent.

It was our aim to make our research also accessible and usable for Heleen's daily life. The affirmation that is central in her daily life is also taken into our research and writing. In establishing this dynamic and reciprocity we could fall back on a relationship and trust that is formed over many years in working together on Heleen's inclusive education trajectory. It is important to stay in close contact with all the family members and take their input seriously when it concerns Heleen and her involvement in the research. Heleen, for instance, participated in editing the film *Swinging Together*, as we found it important to know which images she liked. We always take the time to look for ways in how we can give her the opportunity to (dis)agree with what is going on. We equally make sure that we document and follow her input. While we are swinging and filming, we discuss on several occasions with each other, with the parents, and with the film maker what we are doing and how we can stay respectful to Heleen. The writing itself also implies a great ethical care: we keep discussing what and how we write and how we can talk about Heleen in an affirmative way. Heleen's parents and sister had time to read the article thoroughly before sending it in for peer review. The parts of the text in which Heleen is central are discussed in depth with them. This means we sometimes have to change words or even leave out too sensitive parts when we cannot find a consensus. After the peer review we sat one more time together with Heleen's mother to go through the entire article and also double checked if everything was still okay for Heleen herself. With these examples, we want to make explicit that we interpret our ethical work more as a continual relational process that goes beyond the procedural elements of a one-time ethical approval.

Through concrete practices which Heleen enjoys and is attracted to, we are searching in this paper to make sense of how Heleen experiences the world and how these actions can be used as possible forms of communication. While swinging together we looked for entries and spaces to experiment where we could challenge her and ourselves in our routine ways of communicating and entering relationships: how, for instance, can the ecology of swinging be understood as Heleen's voice? What does this swinging ecology teach us about how Heleen can be in the world and how she wants to participate? Through the swinging we work together with Heleen on finding openings in fixed and normative relations to voice and communication that all the time exclude and marginalize persons labeled as non-verbal. In doing this work, we take neurodiversity as a platform for political change: it not only calls into question the centrality of neurotypicality as grounding structure for existence as we practice it, it also alters how experience, voice and even life in general is defined and valued. We explicitly honor complex forms of interdependence in thinking about voice and create modes of encounter for that difference (Manning 2016: 5–6).

## 2. When Two Hands Touch: Leading-Following Heleen

It is easy to overlook Heleen, as she is easily swallowed up by the stereotypes and diagnostic categories that lie behind the official labels. With a very quick scan, it is apparent that she looks much younger than her peers, and that she can be determined as 'autistic', 'intellectual disabled', and 'non-verbal', but the labels do not capture her way of standing in the world and intuitively showing interest in who and what surrounds her. They do not do justice to her ways of communicating and intra-acting with the world, which seem so fundamentally different from what we know, name, and use as 'voice'. As already stated, Heleen cannot say, write, or type what she wants to say or ask by using language like we are used to and we take for granted. In her context and with the people who know her very well, we learned that this does not mean that she cannot understand others as she is conveyed through language. Most of the time, she makes clear what she wants by making a sound, looking, nodding, just doing the task that was asked, or using her communication device.<sup>4</sup> Her responses or entries in conversations are mostly related to her daily needs (food, preferences, health, etc.). However, *when* she will respond to something or someone is not foreseeable, nor is it always clear *why* she feels addressed and engaged at one moment and remains motionless at another. What works one day (like indicating that she has to go to the toilet or wants to drink something), does not seem possible another day – the triggers and related capacities involved are complex and not predictable. While getting to know Heleen, one needs to rely on information, modelling, and exchange with her family and personal assistants. A lot of stories are being shared on how Heleen participates, relates, and communicates at home, in the regular school, during holiday periods, and so on. There is and continues to be a long and intense search, starting from her family context, in how Heleen can stand in her full strength and get more possibilities to communicate through diverse and multiple entries, multidisciplinary inputs and therapies, strong belief in her capacities, and so on. But how do we describe her voice, her way of relating and the appeal she makes to the material and non-material environments? How can we allow this to take shape in intra-actions, no longer fixed on and attached to an individual performativity? How can we consider her voice, her being and body never as one, never as outside, never as enveloped but always as 'a singular speciation of an emergent ecology' (Manning 2016: 104).

The first time I (first author) met Heleen was when she participated in a series of multimodal workshops I developed with the Finish performance artist Sonja Jokiniemi. The aim was to encounter each other by 'material propositions' in order to explore alternative and more sensory forms of communication and self-expression beyond words.<sup>5</sup> Sonja proposed certain objects (e.g., mirrors, action camera, music instruments) and textures (e.g., velvet, paint, cellophane) that invites touch, and together we experienced their potentiality in communication and making contact. We chose objects and textures because they can provoke responses, where humans sometimes cannot (Lemonnier 2012; Quinn 2017). Additionally, we deliberately did not interpret the objects and textures as mere intermediaries or facilitators, but as agentic in themselves. Objects and textures have what Bennett calls 'thing power'; they are as much 'force as entity, as much energy as matter, as much intensity as extension' (Bennett 2010: 20). When encountering Heleen during the workshops, it stood out how she spontaneously refused to orient herself to the objects and textures in familiar ways. Precisely by engaging in different, more creative ways, Heleen was able to show us what she liked. For instance: she taught us that mirrors are especially attractive to touch with our nose and cheek. That's why we hung small round mirrors across the room, so that, while walking through the space, we could touch those mirrors with our faces and feel and explore their smooth and cold qualities together. We also had big granular paper laying down on the floor. At first Sonja and I were drawing on it, but Heleen made clear that she was not interested in drawing as such. She'd rather sat with us and started to rub the big granular paper with her fingertips, while in this act of rubbing, her whole body started to move. Sometimes closely following the lines of the letters and drawings. Sonja and I followed her in that action of rocking and rubbing, and gradually our bodies rhythmically synchronized.<sup>6</sup> In that moment, the bodily movements, the sound of our fingers on the paper, and the attunement to one-another was shared as an inquisitive and

<sup>4</sup> Heleen sometimes makes use of a Mobi, a communication device and computer with touchscreen combined with the Pragmatic Organized Dynamic Display (PODD). When she wants to communicate something, she can point with her finger to the symbol on the device (e.g.: 'I have a question', 'I have an idea' 'toilet', 'swing', 'food'). However, certain periods in time she don't 'want' to use her Mobi in order to communicate.

<sup>5</sup> We used materials and textures to start a non-verbal dialogue or action. Material propositions do not give information as to how certain objects function in concrete instances but gestures to how they could potentialize; allow us to feel what may be; in that regard, propositions are what Whitehead would term 'lures of feeling' (Truman and Springgay, 2016: 259). The disadvantage of the term material in 'material propositions' is that it tends to overstate the thingness or fixed stability of the material in the propositions, whereas we allude rather to 'vibrant materials' (Bennett 2010: 20) and also see bodies as material. Furthermore, an actant (human and non-human) never acts alone. In other words: matter cannot be understood in isolation but is always part of an agentic assemblage (ibid: 21). We called the workshop space a *dialogical space* and the communication that happened within that space *textured dialogues*.

<sup>6</sup> Here, the approach was not just mirroring (doing exactly the same) what Heleen was doing. It was rather following her in the different use of the objects that were in front of us. In following Heleen the emphasis is on *attunement*, and not on trying to do 'precisely the same' as in mirroring.

oscillating site of communication without-words, sparking new forms of relationality. However, this happened only on a very temporal basis and was accompanied by lots of uncertainties and questions from Sonja and myself, while Heleen most of the time did not seem to be interested.

When the workshop series ended, Heleen took my hand firmly and tried to take me outside with her. At first her determined grip confused me: What did it mean or what did she want, I wondered? Did she wanted to show me something? Did she try to tell me she disliked the workshops? Or was it just a coincidence? Of course, I could continue to ruminate about the 'meaning'. But what is more important is, that it was a moment that caught me up in something that felt like *something*. The significance was in the intensity of the act itself and in what thoughts and feelings made it possible (Steward 2007: 1–4). It is in and because of that touch – a touch which is inseparable from the field of differential relations that constitute it (Barad 2012) – that I decided to follow her.

This following became important in all our future encounters and also affected our research – as we already noted, the research questions on voice and communication have been crafted and intuited in our relation with Heleen. The act of following cannot be reduced to an active-passive relationship but is more closely linked to what Erin Manning calls 'leading-following' (Manning 2009: 30). The concept of 'leading-following' is inspired on the complexities of intra-action in how we move in dance:

We walk. I am leading. But that does not mean I am deciding. Leading is more like initiating an opening, entering the gap, then following her response. How I follow, with what intensity we create the space, will influence how our bodies move together. I am not moving her, nor is she simply responding to me: we are beginning to move relationally, creating an interval that we move together. The more we connect to this becoming-movement, the more palpable the interval becomes. We begin to feel the relation. (Ibid 2009: 30)

In the end it is not clear anymore who is leading and who is following.<sup>7</sup> In leading-following we work with the not-yet known. We also become very aware of slowness, quietness, dead ends. We improvise, begin all over again and again, and try to catch each other's attention. This often demanded serious adjustments of the speed I moved and expected Heleen to move. 'Altering the speed at which the everyday tends to function creates openings for neurodiverse forms of perception. It also makes time for modes of encounter otherwise elided' (Ibid 2009: 15). Of course, these adjustments in speed were not always comforting in an age of perspiring haste, competition, and capitalist logic. Slow inquiry allows being receptive to possibilities that lead to flourishing and emphasizes a relational ontology which holds that people and entities come into being through relationships. It is collective experimentation; it entails foregrounding process rather than product.<sup>8</sup>

To make this process of leading-following more concrete: at a certain moment, Heleen made it clear that she wanted to take my action camera home with her. Because I was interested in what she would do with it, I asked if she and her sister could send me some clips. So Heleen opened a space, I entered the gap and followed her response to it. This led us – Heleen, her sister, and I (first author) – installing a sort of filmic dialogue over the following four months. Without regularity Heleen and I sent each other very short clips of everyday things that we saw and loved. For instance: Heleen sent me a clip in which she showed me the joy she experienced while touching her music organ. In others, she was laughing and swinging, walking at the seaside, or looking at bridges. On my turn, I answered her with clips in which I showed my satisfaction of my fresh red lacquered toenails or I filmed the boats I saw when walking with my newborn. I also filmed things I started to see because of what Heleen and her sister had sent me before. For instance: I answered her clip in which she spins her mobile phone with one in which you saw my bicycle wheel spinning while I was cycling to work. We both shaped, filmed, and shared what mattered to us. Heleen intrigued me and she touched me each time because the clips gave access to how Heleen positioned herself in the world.<sup>9</sup> I wanted to go deeper and further.

<sup>7</sup> From a philosophical perspective this is also a political critique on leadership, and it dismantles the hierarchy between researchers and research subject as it refers to an a-personal field of endless negotiations and transformations (Lepecki 2013: 37).

<sup>8</sup> Slow inquiry is engaged in re-thinking time and space and how we inhabit them in a meaningful way in research endeavors. It is not about doing less or what we do at a more leisurely pace, but being engaged in research activities that are worthwhile (Leibowitz and Bozalek 2018).

<sup>9</sup> Our filmalogue could be seen as a methodological development of well-known methods like, for instance, photo-voice. The filmalogue however exemplifies more purely the leading-following paradigm as it has no ulterior motive other than 'getting in touch' with one another. With photo-voice the researchers takes on the role of facilitator and moderator. In our filmalogue there is more reciprocity in the sense that both provide material and react on each other's material. The roll of the researcher thus becomes that of the participant and vice versa. The methodology in filmalogue allows more diffusion at the level of role determination. Also, while photo-voice is more focused on 'capturing full-fledged stories', our filmalogue is more focused on sharing 'small stories' (Bamberg & Georgakopoulou 2008); immediately reworking slices of experience which arise out of a need to share seemingly uninteresting tidbits. Small stories reflect something about the interactional engagement between the interactants, while for outsiders, these interaction or small stories seems about 'nothing'.



### 3. Opening Up 'Voice' as 'Voice Without Subject'

In our film-dialogue (or filmalogue), Heleen was always filming together with both her sister and her mother. In order to participate, Heleen needs to be in close collaboration with someone else who could support her in her actions.<sup>10</sup> Despite the intense facilitation, I never contested the clips I received as Heleen's voice and expression. Her voice was precisely present in the entanglement of filming, close bodily contact, shared ownership, cell phone, among others. However, to recognize this voice in entanglement, we need a different way of looking at the concept of 'voice' that doesn't fix it as an individual achievement and responsibility, as a proof of intelligence, as the only recognizable way of expressing yourself. How can we understand and recognize voice and communication beyond the dominant verbal understanding in terms of action and response, as a going back and forth between two or more clearly distinct subjects?

Voice is a concept that has historically shifted and transformed as it has passed through particular analytical apparatus.<sup>11</sup> Approaches to qualitative inquiry has often privileged the 'authentic voice' of the humanist subject, assuming that voice can speak the truth of consciousness and experience. In the effort to make (suppressed) voices heard and understood, qualitative researchers have taken up various practices in attempts to 'give voice to' or 'let voices speak for themselves and make them heard' (Mazzei & Jackson 2009: 1). In those endeavors voice is not only understood as present, self-reflective, and authentic, it is also attributed to an individual, be that individual theorized as coherent and stable or fragmented and becoming. Within this understanding of 'voice', Heleen, who is seen as non-verbal, does not have a voice and, as a consequence, doubt arises as to the source of her ideas and thoughts. This line of thinking puts the responsibility with Heleen; it is up to her to make herself heard.

However, along with the crisis of representation (as described, for instance, by Guba and Lincoln, 2005) Mazzei and Jackson (2012) and Spyrou (2011) have emphasized the dangerous assumptions in trying to capture and representing missing voices, which seems to claim that 'authentic voices' exist and can reflect universal truths. In response, some scholars coined the term 'multivoicedness' (Elden 2013; Komulainen 2007) and have started to pluralize voice, in order to highlight already the polyvocal and multiple nature of voice within chaotic and constrained contexts (Mazzei & Jackson 2009: 1). With this they counter the conceptualization of 'voice' as a verbal, rational, and individual characteristic of a speaking subject (Daelman et al. 2020). Post-qualitative researchers, like Mazzei and Jackson, argue that 'multivoicedness' indeed highlights the ways in which voices are not singular, but the concept still implies that voices are still 'there' to search for, retrieve, and liberate. Mazzei and Jackson attempt to resist these too facile ideas about voice, in order to examine what is produced by the trouble of (or with) voice (Jackson & Mazzei 2009: 1–3). In her early work, Mazzei (2003) starts, for instance, to consider the function of silence in research contexts (see also Spyrou 2016). By drawing attention to the silences that occur in research interviews, she challenges the primacy of words as a mode of communication. Together with Jackson, Mazzei also challenges the idea that voice is both intentional and belongs to one individual; rather the concept of voice as a 'singular, stable core self who possesses knowledge that may be transparently known and expressed' (Mayes 2019: 7) must be suspended.<sup>12</sup> In so doing, they position voice rather in a posthuman ontology that is 'understood as attributable to a complex network of human and nonhuman agents that exceed the traditional understanding of an individual' (Mazzei & Jackson 2017: 1090) and thus invites us to think about voice in many forms – as dynamically flowing and polyvocal and messy (Mayes 2019; Mazzei 2016; Mazzei & Jackson 2012). This 'voice without subject', they argue, cannot be possessed but is a thing entangled with other things in a Deleuze-Guattarian assemblage that acts with agential force. In other words: voice is not something that *is*, but rather something that *becomes* in an emergent intra-action with other agents. Voice here becomes a process of connecting bodies, objects, relations, spaces, times, among others. It is a process of becoming (Mazzei 2016; Daelman et al. 2020). With this reconceptualization of voice, Mazzei and Jackson experiment with the affective, corporeal, and material entanglements that confound, exceed, and escape a more traditional analysis of voice. They also explicitly ask whether voice also happens through nonverbal forms: 'Are there not other unthought ways in which our participant voice their thoughts, resistances, and desires?' (Mazzei 2009: 45) However, Mazzei and Jackson did not yet bring this posthuman voice into relation with what it could open for people who carry the label of non-verbal and that is exactly what interest us.<sup>13</sup>

Working with voice without subject, with voice as something that becomes in and through radical relationality, can be uncomfortable at first. However, other ways of connecting and communication emerge: 'Within the register of uneasy communication, the opportunity to body, to sound, to express in a collective voicing is nonetheless available' (Manning 2016: 179). We explore those 'other ways' by leading-following Heleen. In daily life contexts Heleen learns in close relationship with her family, her personal assistants, her teachers and peers using the energy and input of others in order to participate and to contribute both at home and in the regular secondary school. She always needs far-reaching

<sup>10</sup> The people who support Heleen in filming helped her in experimenting, they showed her when I answered, they gave suggestions (but always in close negotiations with what she was doing on certain moments).

<sup>11</sup> For a review of feminist, colonial and deconstructive engagements with voice, see Jackson (2003).

<sup>12</sup> They conceptualize this idea of voice consecutively as 'a voice without organs' (Mazzei 2013), 'a voice without a subject' (Mazzei 2016) and 'a voice in the agentic assemblage' (Mazzei & Jackson 2017).

<sup>13</sup> With her music project *Beyond Words*, Quinn (2019) works on how this posthuman reconceptualization of voice can open up possibilities for people labeled as non-verbal. Quinn uses the term 'post-verbal' instead of 'non-verbal'.

input of other people. She only writes and draws when someone else is holding her hand and supports her while encouraging and facilitating her guidance. She slides along at the table when you put her on the chair and serve her food or put everything ready in front of her. She goes outside when you take her under the arm. She answers questions when you give her yes-or-no options and let her point to one side of her jaw or to one of your hands. If you've been with her long enough, you discover how different her silences can sound and learn to read her movements.

Heleen's body asks for proximity and touch with another (human or non-human) body to start an action and to indicate genuine needs. Touch, here, is for both Heleen and the other body at stake, a matter of response, a condensation of response-ability. What happens in that contact cannot be reduced to an active-passive relationship, nor to a independence-dependence or volition-non-volition dichotomy. Touch here does not create a linear way for reaching certain objectives. Rather, it creates a radical relationality which develops a 'reciprocity in a field of experience that unlocks directs movement in a way that enables communication in and beyond language' (Manning 2016: 142). It is voice as doing (Mazzei & Jackson 2017: 1095). Heleen's voice can be expressed and heard, seen and felt in many forms, her voice is a process of connecting bodies, objects, spaces, and many more. Which touch or object works for Heleen in a particular context and constellation so that it can express its needs, can vary from day to day, from situation to situation and from person to person. You hold on to something that worked and search for ways to get it once more. In Heleen's life there is not one key or (special) method that helps when she gets stuck in a situation, nor is there one way to engage or motivate her. It's about looking again and again for ways to give her space, invite her to contribute and connect with her. It is important to keep open possibilities, as the clinical labels are not sufficient enough; we need to be humble of what we think we know about Heleen, her capabilities and futurities.<sup>14</sup>

#### 4. Swinging Together: Ecology of The Swing and Bodying

During our filmalogue, Heleen showed her enduring love for swinging. That is why I followed her regularly during the hot summer of 2019 to her favorite swings in the public playgrounds in the city of Ghent.<sup>15</sup> Heleen's love for swinging is most of the time interpreted through and connected with her clinical characteristics. It took a very long time before she was able to overcome her motoric fears. Her physical therapist noticed that it also helped in relaxing her muscles, straightening her back, and being able to develop physical strength. So swinging was encouraged because of those effects. In daily life, Heleen needs and develops (new) rituals to find rest and calm down. However, very often she also gets stuck in those. At certain moments in life, Heleen's need to swing becomes very compelling for herself and her surroundings. She insisted (and still insists) on it and starts pointing very frequently to the symbol of 'swinging' at her speech computer. She knows little boundaries and swings until her hands are open and hurt. Heleen's love for swinging is also often seen as an inappropriate childishness, associated with her assumed mental age and her small and frail body.

Perhaps we need to revisit this act of swinging.<sup>16</sup> Not to narrow it down or to interpret and explain it in a deficit way, but to make sense of the swinging movement as a way of relating, thinking, and communicating. In other words, to try to imagine what swinging *does*, to attune to the force of the in-act, to embrace the force of the *what else*:

The unquantifiable within experience can only be taken into account if we begin with a mode of inquiry that refutes initial categorization. Positing the terms of the account before the exploration of what the account can do only results in stultifying its potential and relegating it to that which already fits within preexisting schemata of knowledge (Manning 2016: 29).

Heleen swings determinedly, high and powerful. She stretches her legs and bows them just in time to fuel the backwards motion. The chains squeak rhythmically. Sometimes we swing together, other times I sit in the grass and enjoy Heleen's enthusiasm. The toy objects, which Heleen always carries with her, lay carefully displayed under the swing, clearly in sight at all times. Occasionally, I stop the swing so we can have a drink. Sweat drips down from our foreheads. Sand is sneaking into our shoes. I re-position Heleen on the swing and help to start the movement. Heleen's arms and shoulders act confidently, her gloved hands firmly grasp the chains. She can feel her body and its potential. Because Heleen has difficulty aligning her body to conscious will, she is mostly seen as a non-responsive and non-thinking person, as someone who is little, fragile, and absent. Against this image, we see Heleen transforming on the swing: she becomes a passionate woman, powerful, driven, determined. Here, in the ecology of the swing, something is activated; the body acts beyond Heleen's imagined potential.

<sup>14</sup> In *Learning From My Daughter* (2019), Kittay writes on the importance of humility in order to be open towards the capabilities and possibilities of an individual (226; 236–238; 242). In *Feminist, Queer, Crip* (2013), Alison Kafer works with presumptions about 'future' and 'disability'.

<sup>15</sup> While we went swinging, we were also accompanied by artist Karel Verhoeven, who filmed and photographed our swinging moments. Together we are currently making a video installation out of this material.

<sup>16</sup> With the notion '(re)visit' we allude on 'visiting' as conceptualized by Donna Haraway and Vinciane Despret. To go visting, they argue, is not an easy practice, it demands the ability to find something or someone *actively interesting* and especially those things or subjects most people *already claim to know all too well and completely*, as for instance swinging (Haraway 2016: 127, our italics).





Photos of our swinging together moments, made by Karel Verhoeven.

There is connection and communication: the swing initiates an opening, Heleen and I enter the gap, we follow each other's response. It is not about exchanging words but about moments of communication and about voice as a process of connecting bodies, movements, textures, sweats, sounds merging with the warmth of the sun. Loss of words does not equal loss of response. We use swinging to allow language to go over and beyond words. Heleen laughs out loud, as if the tingles she is searching for through motion bubble up out of her body. She is convinced of the movement in the ongoing. This shaping defies description, the swinging movement is vigorous, frenzied and ineffable; swinging here is itself *expressibility* (Manning 2016: 176–177, our italics).

The body is integrated in all our experiences, also in thinking, feeling, expression, and communication. This means that the body is not just a locus or Heleen's individual body, but rather a field of relations, a dynamic constellation in co-composition with the environment. To emphasize this idea of the body as a form-in-movement, Manning uses the term '*bodying*' (2016: 115, our italics). This term refers more precisely to the edges of language and voice where movement activates a body in the midst of a process of becoming (Ibid 2016: 189). That Heleen has difficulty aligning her body to conscious will does not mean that the activity is devoid of thought, nor does it mean that she is not in awareness or expressing herself (Ibid 2016: 115). Thought, feeling, and expressibility, as Heleen experiences them, are not *in* her mind nor *in* her body, but *across* the *bodying*, 'in the synesthetic sensation that refute the absolute locatedness of body and world' (Ibidem). This thinking-feeling-expressibility is mostly at work on a nonconscious level and cannot be directly articulated in language, with a self-sustaining individual voice, and yet, Manning argues, it is a thinking-feeling-expressing *in its own right*.

Our neurotypical world is extremely engaged with consciousness and thus with intentionality and volition. This means that nonvolitional or pre-intentional (nonconscious) expression in the event are not only undervalued but often totally ignored. Nonconscious thought-feeling-expression is everywhere active in experience, it is a thinking-in-the-act (Manning 2016: 115). This 'nonconscious thinking-feeling-expressing' across experience, is what many philosophers (like Nietzsche) are searching for in walking. Therefore, we could even say that what swinging is for Heleen is equal to what walking is for Nietzsche. In exploring the value of nonconscious thinking-feeling-expressing across experience, Manning draws on Whitehead's process philosophy: thinking is not something that can only be localized in the brain, it is rather present on a more elementary level. Our body and feelings are the basics of our self and consciousness.

Thinking can also be nonconscious, Whitehead says, and experience is so much more than that we acknowledge on a conscious level.<sup>17</sup> In *Process and Reality* ([1929] 1978), he wrote:

[...] that sense-perception of the contemporary world is accompanied by perception of the 'witness' of the body. It is this witness that makes the body the starting point for our knowledge of the circumambient world. [...] For the organic theory, the most primitive perception is 'feeling the body as functioning (Whitehead [1929] 1978: 81).

In Heleen's case, the nonconscious movement of thinking-feeling-expressing is not the problem. The difficulty for her is rather situated in 'the making-conscious of this movement, in the subtraction from the field of relation to the actual occasion' (Manning 2016: 116). But if we take Heleen seriously, we have to value this nonconsciousness, we have to recognize this thinking-feeling-expressing and value the movement of thought, feeling, and expressibility activated by swinging. Only when doing this, we 'tap into the force of a bodying that shapes experience into exuberant potential, [...] in the force of its expression across the precarious chasm of petrification and spark' (Ibid 2016: 182). If we take a neurodiverse stance, we notice that the swing activates a movement of thought and thus that swinging for Heleen is itself thought-feeling-expressibility. Swinging, then, is not a deviation from language and voice, but rather its extension, in co-composition (Ibid 2016: 177).

When we understand and recognize Heleen's swinging as thinking-feeling-expression, we can address her way of using her body and her voice in ways that we were not aware of before. It gives her space and it invites her to contribute and connect on her pace, in her way. It also opens up the narrow definitions that surround both what 'voice' and 'swinging' is and who Heleen is and can become, intra-acting with the world. It is breaking through the hierarchical readings that constantly lock Heleen up in 'not speaking', 'not being able', 'not thinking', 'not responsive', and so on. Of course, we don't want to rule out the possibility that sometimes there can be danger in the many swings.<sup>18</sup> However, we don't want to let it take on the master status that it now often gets. Only then can there be a transformation of thinking, of speaking, of bodying, of becoming-in-the-world-with-others.

## 5. (In)Conclusion

When we only focus on labels and pathology, we turn the field inwards, we stop, and dwell in the judgment of the 'it is' (Manning 2016: 202–203). The work of encountering is then laid out in terms of the already-defined, which means that Heleen is not challenged and could sit in the sofa all day, focusing only on the toy objects around her. Opening up our understanding of 'voice' and taking a neurodiverse perspective with attention to relational ontology is a thinking that focuses on possibilities and the creation of spaces to experiment with Heleen in order to keep searching for opportunities, even beyond the realm of probability or beyond what it should be like. This latter means we work at the limits where the 'what is' can become 'what else'. By revisiting swinging together, we were moving collaboratively, we were active and curious for what could happen. Swinging opens experience to its potential and is affirmative to its core – and as Manning argues: affirmation is the creative force of a reorientation in the event (Ibid 2016: 201). But what happens goes further than the swinging ecology itself; we see that this kind of affirmative experimenting was already there in the struggling of the family for inclusive education, in the way they facilitate Heleen, in the creative choice of support workers, and so on.

This work of inventing and experimenting with 'leading-following', 'voice', and 'bodying' is not always comfortable or comforting, nor does it easily fold into a smooth surface. On the contrary, the purpose is rather that we keep unsettling the 'it is' (Manning 2016: 202). It does not promise openings for potential in a straightforward sense, we saw that there are very often dead ends as well. But however complex and difficult, there are always new straws to cling to and continue. This swinging together itself and the filming of the swinging moments had a direct impact on what was discussed in the family of Heleen. They were curious about why all the attention went to swinging. They were proud about the idea that this desire of their daughter for swinging could mean something. This swinging together was also extensively discussed at a gathering planned to evaluate the latest school year with Heleen, her family, her support workers, and teachers. Heleen proudly showed the photos and clips we made while swinging. The focus was not on the absence of words, but on swinging as expressibility and thus on *moments of communication*, on sparks of new life. This supports Heleen's family in continuing their search, in continuing experimenting together with Heleen. It seems a small thing, but exactly such small sparks are crucial: 'The message of the spark is that something vital is happening that moment and that moment cannot be erased' (Quinn and Blandon 2017: 589).

In working on the reconceptualization of 'voice' with Heleen, we learned how important it is not to search for a magical closure, a final singular form, or (special) method with instructions to follow, but to focus on the relational and procedural. Swinging was procedural because it is 'the following-through of a set of conditions toward repeatable

<sup>17</sup> We would like to thank Ronny Desmet for this insight.

<sup>18</sup> Think about how Barad emphasizes the ongoing work of the past in the present: 'The past is never finished. It cannot be wrapped up like a package, or a scrapbook, or an acknowledgement: we never leave it and it never leaves us behind' (2007: ix).



difference. The procedural [...] is what gives [...] consistency without allying it to precomposed models of formation' (Manning 2016: 89). Looking closely at the swinging of Heleen, we are not looking at how we can repeatedly make a difference and see it happen to other persons labeled as 'non-verbal'. This is not something we can simply transfer, but swinging in the context of Heleen 'activates zones of intensity in fields of relation and directs a follow-through that re-intensifies at every turn' (Ibidem). It opens up new avenues of thought to search through leading-following, bodying, passion, and the intra-actions with world how we can rethink the binary between verbal/nonverbal. We can open spaces we were not aware of before and this can make a concrete difference, not only for Heleen and her family, but for all of us.

### Ethics and Consent

Informed consent has been obtained from all the participants in this research. The use of the photos included is also approved by informed consent. This research was approved by the Ethics Committee for The Social Sciences and Humanities Antwerp University (number SHW\_19\_52) on January 31, 2020.

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### Competing Interests

The authors have no competing interests to declare.

### Author Contributions

Both authors contributed equally to this article. Author 1 was the PI of the participatory research project; author 2 is the coordinator of the participant's inclusive school trajectory and has known the family for more than 14 years.

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